EFFECT OF PEER MENTORS ON KIDNEY TRANSPLANT CANDIDATES

Susan S. Walker, LMSW, Transplant Clinic, Beaumont Hospitals, Royal Oak, MI;

Renautta Wojtylo, RN, BSN, CNN, Transplant Clinic, Beaumont Hospitals, Royal Oak, MI;

Kelly Hendrix, RN, BSN, CNN, Transplant Clinic, Beaumont Hospitals, Royal Oak, MI;

Victoria C. Lucia, PhD, Research Institute, Beaumont Hospitals, Royal Oak, MI

Patients with chronic kidney disease can experience a range of emotions and issues associated with the treatment of their disease. This two-part study investigated the effects of a hospital-based peer mentoring program on time to listing and quality of life for kidney transplant candidates. No significant differences between patients with and without peer mentors were found regarding time to listing or quality of life. It was discovered that race played a role in willingness to accept a peer mentor when offered by the transplant social worker, with more minorities assigned a peer mentor than whites (p = 0.01). However, no significant difference between patients with and without a peer mentor was found in time to listing when controlled for race (p = 0.42).

INTRODUCTION

Patients who have experienced chronic kidney disease can empathize with the range of emotions and issues that confront newly diagnosed patients. The National Kidney Foundation of Michigan (NKFM) Peer Mentoring Program was developed to assist patients with decision making and coping, and to empower patients to take control of their lives and healthcare (National Kidney Foundation of Michigan, 2010). Prospective peer mentoring candidates undergo a one-day training program, focusing on communication skills, empathic listening, values clarification, problem solving, and assertiveness. The peer mentor can then share personal experiences with newly diagnosed patients to help explore their options, as well as deal with the complex psychosocial issues they may encounter. This program has enjoyed remarkable success and has been adopted throughout the United States.

To address the unique needs and issues of prospective kidney transplant patients at Beaumont Hospital's Kidney Transplant Program in Royal Oak, MI, the transplant social worker, in conjunction with the leadership of the NKFM, developed a similar targeted peer mentoring program of their own to assist patients who are in the early evaluation stage of being listed for a kidney transplant or for those who have recently had a kidney transplant. The Beaumont Peer Mentoring Program differs from the state program in that only post-transplant patients are eligible to become peer mentors. The social worker asks pre- and post-transplant nurses to carefully select post-transplant patients they believe are committed to self-management of their chronic illness and transplant, and are capable of being role models and supporting others facing similar medical concerns. These individuals need to be knowledgeable, open, attentive, and active listeners. They must also understand that they cannot give medical advice to others, since others may not have the same experience with transplant or any other treatment. Potential peer mentors are people who can comfortably share their own experiences so that patients facing life with chronic kidney disease will not be so fearful and overwhelmed.

Mentors for the Beaumont program attend a one-day training session. The training is interactive and audience participation is highly encouraged. After completion of their final role play, they are given a certificate of completion and a peer mentor name badge. Subsequently, their names are added to the transplant clinic's peer mentor directory. The transplant social worker uses discretion in matching patients who request peer mentors with people in the directory with similar histories and psychosocial demographics. Mentors are also expected to provide feedback to their transplant social worker.

The primary purpose of this study was to assess the effectiveness of the Beaumont Peer Mentoring Program in helping patients through the pre-transplant listing process. Specifically, it was hypothesized that patients with a peer mentor would be listed sooner than patients without one. Secondary questions of interest were also investigated: 1) Is there a difference in the quality of life of patients with peer mentors compared to patients without peer mentors?; 2) Is there agreement between patients and peer mentors regarding perceptions of the nature of their relationship?

Corresponding Author

Adam Ellis, BS, Research Institute, Beaumont Hospitals, Royal Oak, MI;

METHOD

Sample and Design

The sample consisted of adult pre-transplant patients (\geq 18 years) from a single, large, academic community hospital's kidney transplant clinic who had initial social work evaluation visits between August 2007 and December 2008. A December 2008 cutoff allowed all patients included in the sample sufficient opportunity (minimum 8 months from initial social work evaluation to start of data collection in August 2009) to fulfill requirements to be listed for transplant. Any patients subsequently found not to be kidney transplant candidates by the Transplant Team Committee, or patients who never returned to the transplant clinic for their follow-up evaluation visit, were excluded from the study. In addition, peer mentors who were assigned to any of the study patients were also included in this study.

The study was a two-phase project. The first phase was a retrospective chart review of the identified patient sample designed to answer the primary research hypothesis. The second phase was a prospective data collection study in which living patients from Phase I were contacted by mail and asked to complete a short research survey. A second request was mailed to patients not returning the survey within three weeks. A self-addressed postage-paid envelope was included in each mailing for the patient to return the survey. Out of respect for the patients and the severity of their illness, a maximum of two requests were sent to each patient. In addition, peer mentors assigned to patients included in Phase I were contacted by phone to complete a short survey.

This study was approved by the participating hospital's Institutional Review Board.

Measures

Phase I collected data intended to identify length of time from initial evaluation to listing date (if applicable). Other variables of interest such as comorbidities, demographics, and whether or not a peer mentor was assigned to the patient were also collected.

Phase II included both patients and peer mentors. Patients were asked to complete the Kidney Disease Quality of Life Survey-36 (KDQOL-36) (Hays et al., 1995). This questionnaire was originally developed for use with chronic kidney disease and dialysis patients. However its use has been extended to transplant patients (Fiebiger, Mitterbauer, & Oberbauer, 2004). The KDQOL-36 consists of five content areas, including the SF-12 general mental health and physical health quality of life scales, in addition to burden of kidney disease, symptoms and problems, and effects of kidney disease on daily life subscales. Each of the five content areas is scored on a 0 to100 point scale, with higher values indicating better quality of life. This survey is an accepted way to measure disease-specific quality of life, and has been shown to be a valid and reliable measure of quality of life for kidney disease patients (Barotfi et al., 2006).

Research has shown that conducting the KDQOL-36 over the phone may lead to higher physical health scores, suggesting a response bias (Unruh et al., 2003). Thus, only survey mailings were attempted.

In addition to the KDQOL-36, the patient mailing also included a short survey developed to assess the patient's experience and perceptions of the relationship with the assigned peer mentor, if applicable. Specifically, to assess the nature of the patient/peer mentor relationship the following question was asked of patients with a peer mentor: "How close do/did you feel to your peer mentor before your transplant?" Similarly, peer mentors were asked to complete a short phone survey regarding each of their assigned patients included in Phase I of the study, including the following question: "How close do/did you feel to the patient before transplant?" Patients and peer mentors could choose from the following responses: "No relationship," "Acquaintance/Casual," "Friendship," "Other."

Statistical Analysis

Categorical variables were examined using a χ^2 test when appropriate (expected frequency > 5); otherwise, Fisher's exact test was used. Continuous variables were examined using Wilcoxon rank test, as none of the variables were normally distributed. Median and interquartile range (IQR) were reported. Kaplan-Meier estimates were performed for time to listing, stratified by peer mentor status (assigned vs. not assigned). Diabetes and risk factors that were found to be significant in the univariate analysis were possible confounders, so the Kaplan-Meier analysis was repeated, stratified by each. Race was found to be significant in the stratified analysis, so a race-adjusted Cox proportional hazards model was examined.

A probability value of less than 0.05 was considered statistically significant. SAS version 9.2 (SAS Institute, 2010) was used for all analyses.

RESULTS

The study consisted of two parts. Phase I of the study (retrospective chart review) included 177 patients. There was no statistically significant difference in the number of patients with (n = 85) and without (n = 92) peer mentors (p = 0.60). Phase I sample demographics are included in Table 1. Phase II of the study (prospective survey) included 161 patients, as 16 patients were identified as being deceased prior to the survey mailing. A total of 35 peer mentors were assigned to 85 patients from the Phase I sample. Eight peer mentors were excluded from the study because they were either deceased or contact information was unavailable. Therefore, a total of 27 peer mentors were invited to participate in Phase II. Figure 1 depicts the study sampling structure.

A total of 93 (52.5%) patients in the Phase I sample were listed for transplant through August 2009. Kaplan-Meier estimates were performed to identify differences in the time to transplant listing in patients with and without a peer mentor. At 3 months, 28% of patients with a peer mentor versus 44% of patients without a peer mentor were listed, and at 6 months, 34% of patients with a peer mentor versus 52% of patients without a peer mentor were listed. There was no statistically significant difference in time to listing for patients with and without a peer mentor (p = 0.14). Even after controlling for diabetes, a variable thought to contribute to extending time to listing, there was no significant difference in time to listing for patients with and without a peer mentor (diabetes: p = 0.39; no diabetes: p = 0.38). Univariate analyses found significant differences in sex and race between patients with and without a peer mentor. Kaplan-Meier stratified analysis found no significant difference in time to listing by sex (p = 0.95); however, there was a significant difference in time to listing by race (p = 0.001). At 3 months, 48% of white patients vs. 23% of nonwhite patients were listed, and at 6 months, 54% of white patients vs. 30% of nonwhite patients were listed. Cox proportionalhazards, controlling for patient race, found no significant differences in time to listing between patients with a peer mentor and patients without a peer mentor (p = 0.42).

Surveys were mailed to 161 patients for Phase II of the study (16 were identified as deceased prior to mailing). The return rate, after two total mailing attempts, was 46% (74 returned surveys). Of the 74 returned surveys, 13 declined to participate, and 4 indicated that the patient was deceased. Therefore, the survey completion rate was 36% (57/157). No significant differences were found between responders and nonresponders with respect to peer mentor status (assigned vs. not assigned), gender, race, employment status, hypertension, or diabetes. There was a significant difference (p = 0.02) in median age, with responders being older (median = 58.3 years) than non-responders (median = 55.4 years). There was no significant difference in the number of patients with and without peer mentors, among the 57 patients who completed and returned the survey (p = 0.15).

Telephone surveys were completed with 20 (74%) of 27 peer mentors. The 20 peer mentors reported experiences with a total of 47 patients.

Preliminary analysis was conducted on time from initial evaluation to survey completion between patients with a peer mentor and patients without a peer mentor to ensure that varying lengths of time from the beginning of the pre-transplant process to survey completion was not a potential confounder for quality of life. There was no significant difference in time from initial evaluation to survey completion between patients with a peer mentor (median = 20.5 months) and patients without a peer mentor (22.3 months) (p = 0.21). Wilcoxon rank test found that patients with a peer mentor did not have significantly different quality of life scores compared to patients without a peer mentor in all five quality of life domains (Table 2). The nature of the patient/peer mentor relationship could only be evaluated on 12 patient/peer mentor pairs, as we only had complete data from both respondents on this small subsample. The weighted kappa was 0.41.

DISCUSSION

Prospective kidney transplant patients face an overload of information, responsibilities, and emotions during the initial stages of the process to transplant listing. In order to provide hope, encouragement, and understanding to them, the Beaumont Hospital Transplant Clinic initiated the Beaumont Peer Mentoring Program, a variation on the National Kidney Foundation of Michigan Peer Mentoring Program. While decreasing time to patient listing was not an objective of the program, it was believed that having a support system, which included someone who had experienced the listing and transplant process, could decrease time to listing. However, the data from this study does not support this hypothesis. Patients with a peer mentor were not listed more quickly than patients without a peer mentor. The data also did not support any differences in the quality of life of patients with a peer mentor compared to patients without a peer mentor. There was moderate agreement between patients and peer mentors regarding the nature of the patient-peer mentor relationship, though this finding should be interpreted cautiously, as it was based on a very small sample size.

Several limitations of the study merit attention. First, and perhaps most importantly, we cannot be sure that our variable reflecting that the patient had a peer mentor is pure. It is accurate to the extent that a Beaumont Hospital peer mentor was assigned. However, some patients may have had informal peer mentors available to them; specifically, a family member who has undergone kidney transplant who was utilized as a resource of support. This was not systematically documented in patient records, so the investigators had no way of knowing how many patients who refused a Beaumont Hospital peer mentor fall into this category. For purposes of analyses, these patients were included in the "Peer Mentor Not Assigned" category, which may have attenuated the analyses and contributed to the lack of significant findings. Similarly, once a patient agreed to being assigned a peer mentor, there was no guarantee that they would actually utilize the peer mentor as a resource. Of the 47 patients that the 20 peer mentors were surveyed about, it was reported that there was no contact with 8 (17.0%) patients and an initial contact with no subsequent interactions with 10 (21.3%) patients. Reasons given for this limited contact varied (e.g. patient too tired, left messages and patient never called back). There was no formal documentation from the peer mentors on patients not following through with the assigned peer mentors as a resource. For purposes of analyses, these patients were included in the "Peer Mentor Assigned" category, but they may not have actually benefited from a peer mentor. A more accurate variable for future research might be "Peer Mentor Utilized."

Second, some patients may have had a living donor, which may make them different from a sample of patients who were placed on the formal transplant list and must wait for a deceased donor. Again, this information was not systematically available during the chart review phase of this project, so we were unable to determine if patients with a living donor were likely to be listed more quickly than patients without a living donor.

Third, as with any survey-based research study, especially mail-based surveys, response rate and nonresponder bias is an issue (Asch, Jedrziewski, & Christakis, 1997; Brennan & Hoek, 1992; Groves, Cialdini, & Couper, 1992). As a result, generalizability and reliability of the data may be compromised. However, it was determined early in the design phase that no more than two mailings would be attempted for Phase II.

Despite these limitations, the study has provided important information and an invaluable experience to the transplant team running and supporting the Beaumont Peer Mentoring Program. It is important to remember that the program was not designed to decrease the time to listing for potential transplant patients. While this would have been an added by-product, this was not the program's primary objective. There are several factors that contribute to the success of the program. Some of these factors are controllable (e.g. selection of peer mentor candidates, training), whereas others are not (e.g. other, informal sources of support, whether patients utilize peer mentors as a resource). These factors must be carefully considered and systematically documented in order to show a statistically significant effect. Informal assessments have provided tremendous positive feedback from patients and peer mentors, and the program continues to gain popularity.

In addition, it was interesting to discover how race played a role in the assignment of peer mentors and in time to listing. It has been documented that minorities are distrustful of the healthcare system (Armstrong et al., 2008; Boulware, Cooper, Ratner, LaVeist, & Powe, 2003; Doescher, Saver, Franks, & Fiscella, 2000). However, in our sample there was a significant difference by race in patients with and without a peer mentor. Specifically, minorities (predominantly African-American, 89% in our sample) were more likely to accept a peer mentor than to decline when mentors were offered as a resource by the transplant social worker. Unfortunately, it was also found that minorities took significantly longer than whites to complete the requirements to be listed for transplant. However, there were no significant differences in time to listing between patients with and without a peer mentor, when controlling for race.

Further research in this area is needed. While a randomized controlled trial would provide the strongest data in determining the effectiveness of the program, this may not be the most ideal study design for a program that was developed as a voluntary resource for patients. There could be diminished benefit to the patient and the peer mentor if the patient was required to participate in such a program. More complete documentation about potential confounders would strengthen a retrospective study.

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| | Total Sample N = 177 n (%) | Peer Mentor Assigned <i>n</i> = 85 <i>n</i> (%) | Peer Mentor Not Assigned n = 92 n (%) | p value | | |
|---------------------------|----------------------------------|--|--|---------|--|--|
| Sex: | | | | | | |
| Male | 113 (63.8) | 47 (55.3) | 66 (71.7) | 0.02 | | |
| Female | 64 (36.2) | 38 (44.7) | 26 (28.3) | | | |
| Race: | | | | | | |
| White | 82 (49.4) | 33 (39.8) | 49 (59.0) | 0.01 | | |
| Nonwhite | 84 (50.6) | 50 (60.2) | 34 (41.0) | | | |
| Comorbidities: | | | | | | |
| Diabetes Mellitus | 75 (42.6) | 40 (47.6) | 35 (38.0) | 0.20 | | |
| Hypertension | 137 (77.8) | 66 (78.6) | 71 (77.2) | 0.82 | | |
| Employment Status: | | | | | | |
| Working Full Time | 37 (31.1) | 17 (29.3) | 20 (32.8) | 0.22 | | |
| Working Part Time | 4 (3.4) | 3 (5.2) | 1 (1.6) | | | |
| Disabled | 19 (16.0) | 13 (22.4) | 6 (9.8) | | | |
| Retired | 40 (33.6) | 19 (32.8) | 21 (34.4) | | | |
| Student | 1 (0.8) | 0 (0.0) | 1 (1.6) | | | |
| Not Working | 18 (15.1) | 6 (10.3) | 12 (19.7) | | | |
| Age at Evaluation (Years) | 57.2 | 57.8 | 56.4 | 0.36 | | |
| Median (IQR) | (46.8, 62.6) | (48.9, 62.6) | (46.1, 62.2) | | | |

<u>Table 1.</u> *Patient Characteristics (N = 177)*

Note: IQR = interquartile range

| | Total N = 57 Median (IQR) | Peer Mentor Assigned n = 23 Median (IQR) | Peer Mentor Not Assigned n = 34 Median (IQR) | p value |
|--|---------------------------------|---|---|---------|
| Mental Health Quality of Life | 53.7 | 52.2 | 54.4 | 0.53 |
| | (44.5, 56.3) | (45.7, 56.0) | (44.5, 56.8) | |
| Physical Health Quality of Life | 39.0 | 38.2 | 39.8 | 0.76 |
| | (30.4, 52.0) | (32.6, 52.3) | (29.1, 52.0) | |
| Burden of Kidney Disease | 62.5 | 56.2 | 65.6 | 0.30 |
| | (31.2, 87.5) | (25.0, 87.5) | (37.5, 87.5) | |
| Symptoms and Problems | 81.2 | 77.3 | 83.3 | 0.10 |
| | (72.2, 91.7) | (60.4, 87.5) | (77.1, 93.2) | |
| Effects of Kidney Disease on Daily Life | 81.2 | 75.0 | 81.2 | 0.20 |
| | (56.2, 89.3) | (43.8, 87.5) | (59.4, 93.8) | |

| Table 2. Kidney I | Disease Qual | lity of Life | by Peer l | Mentor Status | (N = 57) |
|-------------------|--------------|--------------|-----------|---------------|----------|
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Note: IQR = interquartile range

